

**Web Dissemination of Federal HIV/AIDS Treatment
Guidelines: A Dynamic Model
Poster Session**

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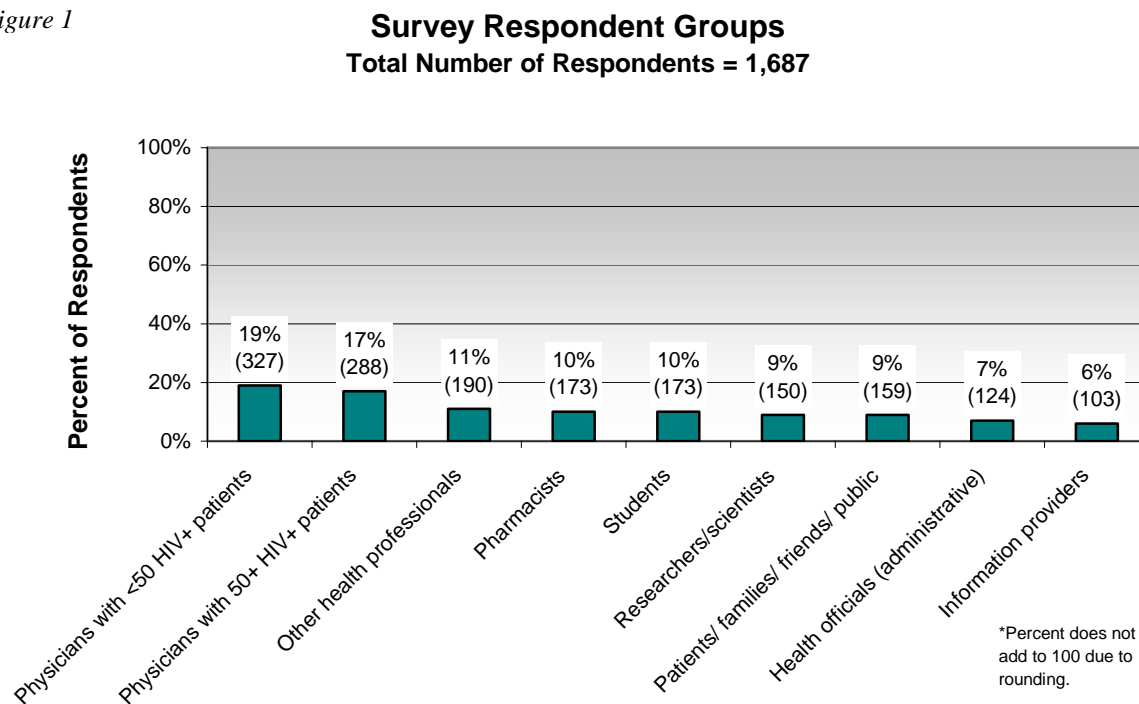
The U.S. Department of Health and Human Services (DHHS) issues Guidelines to help health care providers treat people living with HIV in the United States. There are separate antiretroviral treatment Guidelines for adults and adolescents, children, and pregnant women. In addition, there are guidelines for prevention and treatment of opportunistic infections, for post-exposure prophylaxis, and for testing. The Guidelines are considered “living documents” because they are updated frequently to reflect the latest research and experience with HIV/AIDS prevention and treatment. All of the Guidelines and related documents are available on the *AIDSinfo* Web site.

The Guidelines are primarily used by health care providers, including physicians, nurses, dentists, and pharmacists. Other users include researchers and scientists; people living with HIV/AIDS, family members, friends, and the public; administrative health officials; and information providers, such as community-based organizations and health advocates.

In order to learn more about the usage of HIV/AIDS treatment guidelines, the Aspen Systems Corporation Research Department conducted *Analysis of HIV/AIDS Treatment Guidelines Survey* (1) in 2002. This online survey was designed to obtain information and feedback from Guideline users. The survey included questions about the characteristics of users, how they learned about the Guidelines, how often they accessed the Guidelines, and suggestions they had for improving the Guidelines-related services.

The *Analysis of HIV/AIDS Treatment Guidelines Survey* (1) data identified the various groups that accessed the HIV/AIDS Guidelines via the Internet. As expected, the largest groups of survey respondents were health care providers and other health care professionals. As shown in Figure 1, 19% were physicians with fewer than 50 HIV/AIDS patients and 17% were physicians treating more than 50 people living with HIV. Other respondents included pharmacists, researchers/scientists, and students.

Figure 1



Development of Guidelines

To develop and update each set of treatment Guidelines, DHHS convened panels of HIV experts from across the country. The expert panel includes physicians, pharmacists, researchers, and HIV treatment advocates. Their diverse backgrounds enable panel members to consider a variety of perspectives during the Guideline development process. The *AIDSinfo* staff members assist with producing Guideline documents, as well as posting the Guidelines and related documents on the *AIDSinfo* project Web site.

The panel members use a wide variety of sources to develop the Guidelines. On an ongoing basis, they study the latest drug information submitted to the U.S. Food and Drug Administration (FDA), evaluate early results of clinical trials, review information presented at conferences, examine articles published in professional journals, and communicate with other HIV/AIDS experts throughout the world.

From the beginning, the *AIDSinfo* project staff assisted with the development and dissemination of the Guidelines. Before each set of guidelines is finalized, *AIDSinfo* staff post the draft Guideline documents on the *AIDSinfo* Web site for review by health care providers, people living with HIV/AIDS, and others. Then, panel members carefully review the feedback and make modifications before releasing the final documents. Figure 2 shows the Guideline development process.

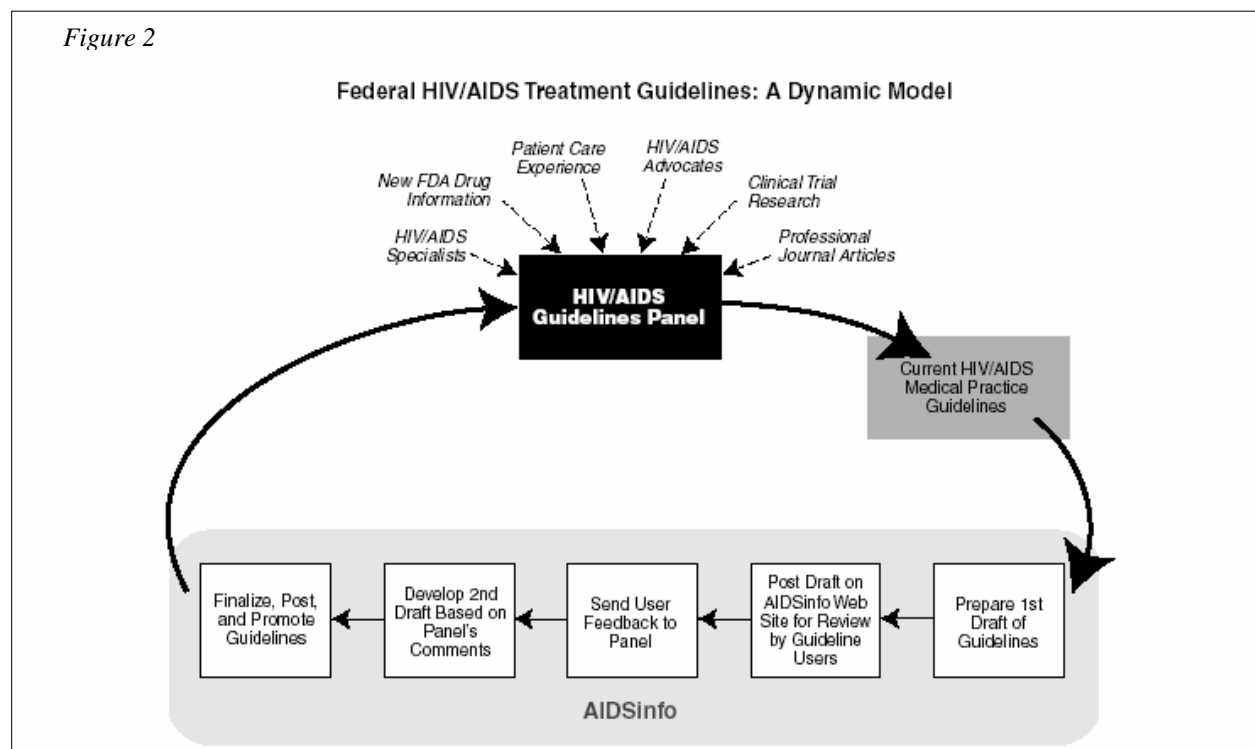


Figure 2: Federal HIV/AIDS Treatment Guidelines: A Dynamic Model

Disseminating the Guidelines

When the first Adult and Adolescent Guidelines were developed in 1997, panel members knew they needed to disseminate the information quickly so health care providers would have access to the expanding number of treatment options as soon as they were available. They chose the Internet because the relatively new Web technology allowed them to convey the Guidelines, updates, and related materials throughout the world in seconds.

Since 1997, the number of people accessing and downloading Guidelines has grown significantly. By 2000, more users were accessing the Guidelines via the Internet than requesting them by mail. The following chart (Figure 3) shows the increase in the number of Guidelines downloads from 197,954 in 1999 to more than 1.1 million in 2004.

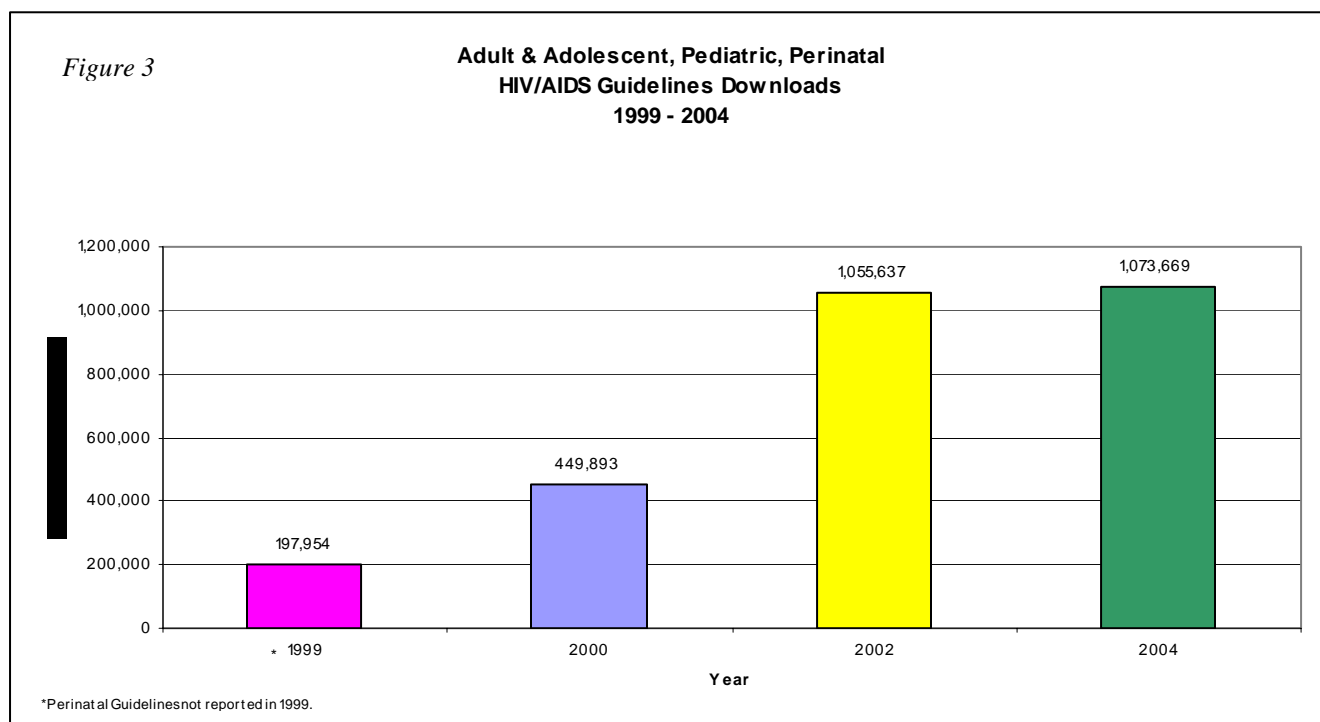


Figure 3: Adult & Adolescent, Pediatric, and Perinatal HIV/AIDS Guideline Downloads

How Guidelines Are Used

The Guidelines survey showed that the various respondent groups used the Guidelines for different purposes. Almost 75% of the physicians, researchers/scientists, and health officials said they used the Guidelines to review the current state of HIV/AIDS knowledge. Seventy-nine percent of pharmacists, 68% of physicians with fewer than 50 HIV/AIDS patients, and 62% of other health care professionals used the Guidelines to get the latest drug treatment information. A majority of the patients, family, friends, the public, and students said they used the Guidelines for general information.

The results of the American Customer Satisfaction Index (ACSI) survey (2) posted on the *AIDSinfo* Web site from 2003-05 confirmed the Guidelines survey results. The data showed that physicians and other health professionals visiting the site used the information for both patient care and for information on treatment options.

Improvements

Since the first Guidelines were released, the *AIDSinfo* staff members have worked closely with the panels members to enhance and improve the Guideline documents, as well as to take full advantage of emerging technologies. The Guidelines survey showed that, as with usage, desired improvements differed by user group. Forty-two percent of the patients, family, and public respondents reported that a consumer version would be most helpful to them. Health professionals, including pharmacists, physicians, and others, were most interested in obtaining information that could be downloaded into personal digital assistants (PDAs).

Pharmacists, patients, family members, and the public asked for more drug information. Other respondents suggested including summaries of information on a pocket-sized card or single sheet, adding links to published journals, and modifying the layout or organization.

Using these suggestions as a guide, *AIDSinfo* staff members have:

- Created downloadable versions for PDAs and pocket PCs
- Offered summaries of new Guidelines and clearly highlighted changes so users could easily identify and familiarize themselves with the latest information
- Enhanced the HIV/AIDS drug information to meet the needs of health professionals, consumers, and Spanish speakers
- Provided easier options for ordering Guidelines and related documents online
- Developed consumer fact sheets that present Guideline information in lay language
- Initiated the *AIDSinfo* E-News and a weekly At-a-Glance newsletter to alert Guideline users about updates
- Enhanced the *AIDSinfo* Web site to draw attention to Guideline-related news and updates

The response to these changes has been positive, as evidenced by the growing number of Guideline users and increasing number of downloads.

Summary

In 1997, the Adult Panel realized the need to quickly disseminate information about scientific discoveries that expanded the understanding of HIV treatment and standards of care. They turned to the Internet, a technology that had not been used before, to disseminate rapidly changing information.

As they prepared the first Guidelines for treating HIV-infected adults and adolescents, the Panel conceived the concept of developing these as *living documents*--documents that use the Internet's capabilities for real-time information dissemination. The Internet allowed for flexibility in updating information as rapidly as the science became known and quickly making that information available to health care providers.

The Panel's vision revolutionized the way that information about the changes to the medical management of HIV was developed and delivered. It now serves as a model for treatment guidelines for many other diseases.

References

1. Analysis of HIV/AIDS Treatment Guidelines Survey. Aspen Systems Corporation Research Department, October 2002, Unpublished.
2. American Customer Satisfaction Index (ACSI) Survey data from online survey posted on *AIDSinfo* Web site. November 2003- present, Unpublished.